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The Parental Experience of Having a Child Diagnosed with Type 1 Diabetes

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Abstract

Currently, Type 1 Diabetes Mellitus (T1DM) is one of the most common chronic illnesses diagnosed in children. The long-term implications for the child are numerous, and a diagnosis involves many medical decisions and technical management procedures that require a caregiver to assume the bulk of the responsibility. By focusing on the personal and lived experiences of parents and guardians of children with T1DM who live in Vermont, this research continues to further understand this overlooked population and can be used help parents to reflect and possibly provide insight into coping strategies and ways to improve their quality of life. It also helps to reinforce and validate previous findings on this topic. This was a qualitative study in which virtual interviews with 12 participants were conducted. The results revealed that caregivers were greatly affected and experienced a variety of intense emotional responses corresponding to the 5 stages of grief framework. This is important for providers to know in order to understand how to best support parents, who are largely responsible for the labor-intensive self-management needed in a pediatric diagnosis of T1DM. Future research could focus on identifying and implementing specific ways in which to adequately support this population.

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Chapter 1: Introduction and Purpose

Currently, Type 1 Diabetes Mellitus (T1DM) is one of the most common chronic illnesses diagnosed in children. There are estimates that indicate around 86,000 children under the age of 15 are newly diagnosed with this disease every year (Iversen et al., 2018). This number continues to grow, and trend analyses indicate a disproportional increase in number of new diagnosis in younger children, particularly in those of preschool age (Iversen et al. 2018, Marshall et al. 2009, Rankin et al. 2014, Smaldone & Ritholtz, 2011).

T1DM is a chronic disease that is identified as the complete autoimmune destruction of pancreatic beta-cells, leaving an individual unable to produce insulin themselves, thus requiring the use of exogenous insulin to live (Lee & Hwang, 2019). A diagnosis of T1DM is life-long, interrupting every part of a child's daily life. There are significant implications for both short and long-term health risks related to the diagnosis, which requires the constant management of blood glucose levels (Marshall et al., 2009). These include, among others, an increased risk of developing subsequent autoimmune diseases (Krzewska, & Ben-Skowronek, 2016), a number of ophthalmologic complications (Geloneck et al., 2015), and an increased risk of cardiovascular diseases (Sousa et al., 2019). The impact on both the child and the family is considerable (Ayala et al., 2014), necessitating many medical decisions and technical procedures that require the parents to assume the bulk of the responsibility for overseeing the child's management of blood glucose levels (Rankin et al., 2014).

Because of this heightened responsibility, previous studies have examined different aspects of the parent experience and the impact these responsibilities have on both them and their child. Due to constant blood glucose tests, administering insulin, counting carbohydrates and managing activity levels, having a child with T1DM comes with added parental duties. A

multitude of studies have found that there are higher incidences of stress, anxiety, and depressive symptoms among parents who have a child with T1DM, the implication of this being that this diagnosis affects the family as a whole (Iversen et al. 2018, Lindstrom et al. 2017, Smaldone & Ritholz, 2011).

It is acknowledged that while there is a considerable amount of previous literature on the lives of youth with T1DM, there is less research available on the effects of the child's diagnosis on the parents and their lives (Helgeson et al., 2012). While numerous studies agree that future research should continue to explore the perspectives of parents, so as to better understand their lived experience (Ayala et al. 2014, Iversen et al. 2018, Marshall et al. 2009), they also recognize there have been limitations in past studies. In addition, much of the research available has been done in other countries or particular parts of the United States, leaving a gap in the understanding of the experience in other regions.

Moving forward, there needs to be additional qualitative research done surrounding the parents of children with T1DM. There are several factors to consider when it comes to the overall experience of this specific population, and any opportunity to expand the knowledge base and provide a look into the different aspects of care is important. By designing a study looking at the lived experiences of those who currently reside here in Vermont, this research continues to further our understanding of this overlooked population and can be used to reflect on the care provided in addition to providing insight into coping strategies and ways to improve their quality of life. Asking questions pertaining to the lived experience of parents in Vermont can help to recognize opportunities for improvement and work to enhance T1DM care following a diagnosis.

Aim of study: The aim of the study was to explore the experiences of parents and guardians of children with T1DM that live in Vermont.

Chapter 2: Literature Review

Introduction

Type 1 Diabetes Mellitus (T1DM) is a serious and life-long health condition that affects how the body produces and responds to insulin, making it difficult to regulate blood glucose levels as a result (CDC, *What is Diabetes?*, 2020). This literature review will be focusing on and discuss prior research concerning the impact and risks of having to manage a chronic condition such as T1DM, as well as the parental experience following the diagnosis of a child.

It is evident through research that both short and long-term risks of poor diabetes management are numerous and can seriously impact the morbidity and mortality of an individual, even in pediatric cases. In addition to the added risks, the necessary care management responsibilities that include the administration of daily insulin, regular blood glucose level checks, and monitoring both carbohydrate intake and activity levels are extremely demanding and stressful. The majority of these responsibilities fall on the parents and guardians of children diagnosed, and it has been found that this has a negative impact on stress levels and the overall mental health of these parents. Specifically, feelings of burnout in parents are a common manifestation, characterized by emotional, physical, and mental or cognitive exhaustion (Lindstrom et al., 2017). Clearly, the implications of a T1DM diagnosis involve much more than just the long-term health of the child. The parents are also affected in perhaps a more substantial way than is currently recognized and supported by the healthcare system. This is where both previous and future research could help to educate those who interact with this population on how to best assist them through this life-changing process.

Type 1 Diabetes Mellitus

T1DM, previously known as juvenile or insulin-dependent diabetes, is classified as an autoimmune disorder and is most commonly diagnosed in children and young adults (International Diabetes Foundation, 2020). T1DM is a health condition that no one knows how to prevent and for which there is currently no cure. It is caused by the body's immune system attacking and destroying the beta cells of the pancreas, which then halts the production of insulin. As such, requiring either daily insulin injections or the use of an insulin pump is needed to manage blood glucose levels (CDC, *Type 1 Diabetes*, 2020). T1DM currently affects millions of individuals worldwide and is one of the most common chronic conditions diagnosed in children, with the incidences continuing to rise (Iversen et al., 2018). Unlike other chronic illnesses, T1DM is largely self-managed and is extremely labor-intensive, requiring a variety of daily blood glucose tests. This has a considerable impact emotionally on those who are diagnosed as children, as well as their family members, in particular their parents/guardians (Ayala et al., 2014). It is well known that the proper management of T1DM is extremely important, and if not managed adequately, it can lead to both short and long-term health risks (Marshall et al., 2009).

The Impact and Risks of a Diabetes Diagnosis

The experience of managing T1DM comes with a lot of added responsibility for both the child and the caregiver. Not only does one require insulin, adjusted daily, to avoid hypoglycemia and hyperglycemia, a diagnosis of T1DM also requires at least four blood glucose level checks a day, counting carbohydrates any time food is eaten, and the monitoring of activity levels (Ayala et al., 2014). Along with the short-term impacts and lifestyle changes for individuals diagnosed,

there are longer term health risks as well, including the development of other chronic diseases, retinopathy, and risk factors for cardiovascular complications (Jones et al., 2019, Krzewska & Ben-Skowronek, 2016, Šimunović et al., 2018,). In fact, complications of T1DM are one of the biggest public health concerns today and lead to higher rates of mortality later in life (Šimunović et al., 2018). For example, a diagnosis of T1DM has been shown to increase the risk of acquiring other chronic autoimmune diseases. In a study conducted by Krzewska and Ben-Skowronek (2016), it was found that the co-existence of any of these diseases with T1DM impairs blood glucose control, and diabetes management can deteriorate as a result. Therefore, it is important to monitor autoimmune responses in those diagnosed as other organs may be affected furthering a negative effect on the individual (Krzewska & Ben-Skowronek, 2016).

Another long-term effect of childhood onset T1DM is an increased risk of early cardiovascular disease due to poor glycemic control, increasing the overall risk of mortality (Sousa et al., 2018). A research study conducted by Jones *et al.* (2019) found that there were already significant risk factors present for cardiovascular disease at diagnosis in up to 60% of children screened, with a considerable number either overweight (33.8%), hypertensive (20.5%), or reporting abnormal cholesterol levels (63.5%). Notably, annual increases in blood pressure were significantly higher in black children, and, as such, more attention should be paid to the ethnic variations in disease processes when calculating risk (Jones et al., 2019). Another longitudinal study by Sousa *et al.* (2018) looked at the difference in hemoglobin A1c (HbA1c) levels of those in conventional versus intensive diabetes therapy, and how it affected their level of cardiac autoantibodies, which are associated with a higher chance of cardiovascular disease. They were able to conclude that positive cardiac autoantibodies are associated with an increased

risk of cardiovascular diseases later in T1DM, and levels should be monitored to avoid complications.

Along with heightened cardiac risks, children diagnosed with T1DM are at an increased risk of experiencing a variety of long-term ocular complications including retinopathy, cataracts, glaucoma, and macular edema, among others (Šimunović et al., 2018). In a study looking at diabetes related ocular changes in a group of children with and without a diagnosis of T1DM, there were a few key differences found (Akil et al., 2016). First, the levels of intraocular pressure were increased in the diabetic group, which could be a risk factor for retinopathy. They also reported that Schirmer test readings were decreased, indicating the presence of dry eye syndrome in the diabetic group, which can also correlate with diabetic retinopathy. Through the study it was concluded that children with T1DM may be at a greater risk of neuropathy and retinopathy and, if not treated early, these could progress to visual disturbances and even blindness. Frequent ocular screenings were recommended as a result for a timely diagnosis of any possible complications (Akil et al., 2016). Since many of these health risks are tied to adequately managing blood glucose levels, it is important to remember that, in the case of a pediatric T1DM diagnosis, the brunt of the management care is placed on the parents or guardians.

Experience of Parents and Guardians in the Care of T1DM

It is acknowledged that while there is a considerable amount of previous literature on the lives of youth with T1D, there is less research available about the effects of the diagnosis of a child on the parents and their lives (Helgeson et al., 2012). However, it is understood that the primary responsibility of providing quality management falls on the parents of those with T1DM who are younger than 13. Evidence from previous studies has shown this to have a negative

mental impact on these caregivers, leading to feelings of fear, isolation, self-doubt, heightened stress and anxiety, and symptoms of burnout and depression (Boogerd et al., 2015, Iversen et al. 2018, Lindstrom et al. 2017, Smaldone & Ritholz, 2011). This in turn can affect the psychosocial wellbeing of the parent and negatively influence the diabetes care provided to the child, potentially leading to altered blood glucose management (Boogerd et al., 2015). In the study conducted by Boogerd et al., (2015), information was gathered qualitatively to obtain the parent perspectives regarding their needs and preferences in the care of their child with T1DM. The summarized strategies gathered from the parents included the healthcare team better addressing the wellbeing of both the children and the parents from diagnosis onwards along with facilitating peer support groups locally with others in the same situation. This research highlighted the importance of not just supporting the child after a diagnosis, but the family prospectively as well.

In another study, almost one third of mothers with newly diagnosed children reported some depressive symptoms, and it was acknowledged that the challenges imposed by T1DM can be overwhelming for many (Smaldone & Ritholz, 2011). A common experience for parents in this study prior to a diagnosis involved fear surrounding the health of their child and frustration with primary pediatric providers for minimizing these fears, sometimes causing a delay in their child's diagnosis. In some cases, these providers even blamed the caregiver for the way their child was acting before a diagnosis was made, not listening to parents and sympathizing with what they were experiencing, instead simply dismissing it as a lack of parental expertise (Smaldone & Ritholz, 2011). Many parents described feeling self-doubt while adjusting to delivering diabetes care following their child's diagnosis, feeling that nobody else could fully understand the necessary care, and feeling isolated from others (Smaldone & Ritholz, 2011). In another qualitative study, it was found that parents felt they needed more reassurance from

providers immediately following their child's diagnosis but before any further information was given (Rankin et al., 2014). These findings suggest that healthcare professionals should be taking the time to ensure that parents' emotional needs are met, and that informational support is provided for the parents in order to implement acceptable diabetes care for the health and well-being of their children (Rankin et al., 2014).

Another important aspect of pediatric T1DM care is the potential for parental burnout. It was recorded that nearly one fifth of parents note psychological distress within the first few years after their child is diagnosed, and that burnout symptoms have been found to be prevalent (Lindstrom et al., 2017). Many of the parents stated a need for control stemming from a fear of any complications, both short and long-term, as well as feeling a fear of failure as a mother (Lindstrom et al., 2017). Working in the healthcare profession it would be important to monitor for symptoms of burnout and how self-esteem and control issues could accompany these. It is vital for both providers and other family members to remember that the parents or direct caregivers are an extremely important part of pediatric T1DM management, and that their mental and physical health need to be maintained in order to best care for their child. While research has helped to highlight the importance and need for further quality care and support for this population, future research is indicated and could be used to compare and contrast the experiences of these parents while also providing valuable insight into coping strategies and possible ways to improve their overall quality of life.

Conclusion

T1DM is a multi-faceted condition, and the complexity of the care required in order to maintain good health does not make things easy, especially for caregivers of children with the

diagnosis. This has been shown to be extremely stress inducing and can take a toll on the mental well-being of caregivers. However, the experience of individuals in this population can be so diverse and personal. Future research can help to further the understanding on how to best support caregivers so that they can best support their children.

Chapter 3: Methods

Design

This was a qualitative study, centered around interviews conducted with parents and guardians of children with a T1DM diagnosis currently living in the state of Vermont. IRB approval was obtained by the Principal Investigator (PI) prior to reaching out to any possible participants, and all approved procedures were strictly adhered to for the duration of the study.

Participants

To participate in this study, individuals were required to be adults who are the parent or guardian of a child diagnosed with T1DM. The date of the child's diagnosis had to have been within the last 25 years. Participants had to have the ability to verbally give consent and independently engage in interviews, and were expected to be of varying ages, ethnicity, education level, and economic status. All participants had to currently reside in the state of Vermont. No potentially vulnerable or special populations were included in the study. No cultural and linguistic considerations were necessary.

Participants were identified and recruited through collaboration with a Certified Diabetes Educator at the University of Vermont Medical Center, collaboration with the Vermont Family Network, by reaching out to local school nurses, and through word of mouth. The goal was to recruit and interview between 8-12 qualified and willing participants. The PI provided each contact with a short description of the study and study contact information for them to disseminate among their connections within the potential participant population. At this point, the PI and each participant set up a time and decided on a format for the interview, either by video conference or over the phone.

For the purposes of this study, verbal consent was obtained. The PI sent out an information sheet that included a description of the research project and their role as a participant prior to the interview and reviewed the consent form with the participants if needed. Participants were given as much time as they needed to review the consent document, ask questions, and discuss the study before providing consent. Once verbal consent was given, the interview ensued.

Procedures

Participants were contacted and scheduled for an interview at a time and date that was convenient for each individual. Each participant was interviewed individually either over phone or video call in a quiet room with little to no distractions. The interviews were all structured around a pre-determined list of questions that are included in the Appendix.

All interviews were recorded through audio recordings and deleted following transcription. Each interview lasted anywhere from 30 to 60 plus minutes, depending on the length and depth of responses from participants. At no point was any participant video recorded. Regardless if the interview was conducted over the phone or by video call, the participant was asked for their verbal consent and reminded that they were being audio recorded for the purposes of this study. These recordings were kept secured by the PI at all times throughout the research project and were erased upon transcription of the data.

Analysis

This was a qualitative study consisting of 12 interviews with parents of children with T1DM. Unexpectedly, a large number of responses were received following recruitment, and there were many more individuals willing to participate than could be interviewed. From the

pool of interested participants, the PI choose a sampling that represented a variety of situations including different ages of their children at diagnosis and varying lengths of time following the diagnosis. There were also a few potential participants who did not meet the stipulation of living in Vermont and had to be excluded for that reason.

Interview data collected was then analyzed by taking the recordings, de-identifying and transcribing them, and then coding the transcriptions to be organized into themes. The coding process consisted of grouping common answers and key words that participants shared, leading to trends and patterns being identified, and eventually overarching themes. Through this method of coding, the themes that began to emerge fit into the general framework of the 5 stages of grief (Gregory, 2021). These themes are examined through this specific framework, which became the organizational structure of the results chapter. This process was done in a manner to keep all comments anonymous in order to protect the privacy of the participants.

Chapter 4: Results

Participants

The adult participants that were interviewed for this study were of varying ages, with a mean age of 45 years old. Of the 12 participants, 11 of them self-identified as female (F) and 1 as male (M). Demographic questions were also asked about their children diagnosed with T1DM, the range of ages at diagnosis being anywhere between 1 and 15 years old. Table 1 below displays this data in more detail.

Table 1: Participant/child demographic data

Participant Number	Age of Adult Participant	Sex of Adult Participant	Current Age of Child	Age of Child at Diagnosis	Sex of Child
1	74	F	38	15	M
2	51	F	10	1	F
3	39	F	6	4	M
4	46	F	21 & 18	11 & 11	M/M
5	40	F	6	5	F
6	47	F	13	13	M
7	49	F	17	3	M
8	31	F	4	1	M
9	42	F	15	9	F
10	41	F	9	5	M
11	40	F	11	7	F
12	43	M	16	8	M

The 5 Stages of Grief Framework

Following an in-depth analysis of the interview data, it became clear that many of the themes found correlated with the stages of grief framework created by Elisabeth Kübler-Ross (Gregory, 2021). Grief experienced by this population most likely falls under the categories of either anticipatory or disenfranchised grief, due to grieving the loss of what they thought their child's future would look like and many parents' grief going unacknowledged. The framework consists of 5 stages: denial, anger, bargaining, depression, and acceptance.

Stage 1: Denial

Denial is often used as a mechanism to protect the individual experiencing loss or grief, and encompasses feelings of avoidance, confusion, shock, and a fear of the unknown. This stage was not one that was experienced in the "typical" way by this population, as parents of children who are diagnosed with T1DM are not given the chance to outright deny their new reality. It is vital to their child's health that they begin to manage the disease as soon as possible, leaving little time for caregivers to process this new information, let alone experience this stage in the grieving process. In this stage, two main subthemes emerged – The Intense Education Process and Parental Fear and Anxiety.

The Intense Education Process

Something talked about extensively by those interviewed was the almost immediate and incredibly overwhelming education process. Once a diagnosis of T1DM is confirmed, and depending on the acuity of the situation, families are brought into the hospital as quickly as possible to receive medical attention and training. The initial experience described included

meeting the healthcare team, consisting of a pediatric endocrinologist and diabetes nurse educators, and then swiftly launching into hours of intense training. This occurred sometimes just a few hours after these parents received the life altering news that their child was diagnosed with a chronic illness. Many parents described feelings of devastation and shock, their emotional capacity exceeded, and then being expected to sit for hours at a time to learn the abundance of complicated skills now required to take care of their child.

“The diabetes educator we worked with, she said at one point it was like drinking water out of a fire hose and that summed it up perfectly...it was four days of just intense learning on top of the emotional context of having a child just being diagnosed with diabetes.” (Participant #2)

Parental Fear and Anxiety

Along with feelings of shock and confusion after the diagnosis of their child, parents did discuss feelings of fear around taking care of their child, and how their actions now felt like they had larger consequences than before. Participants were aware of the negative impact poor management has on the long-term health of individual with T1DM, and many felt pressures to keep glycemic control within specific, and sometimes unrealistic, parameters. There was underlying anxiety experienced by many of the caregivers within everyday activities such as going out to eat, soccer practice, or sending their children back to school. Parents explained feeling on edge nearly all the time, but especially at night when they had to make sure to wake up periodically to check their child’s blood glucose. There generally was a lot of anxiety and fear experienced by this population, often described as being repressed in front of their children, which could contribute to certain negative mental health outcomes.

“[I was] scared as hell. When we were first discharged, I felt very overwhelmed. I felt scared to leave the house with him, scared to go to dinner...the overwhelming feeling that my child would pass away in the middle of the night, or that I'd miss an alarm. Or I'd sleep through an alarm because I was just beyond exhausted.” (Participant #3)

Stage 2: Anger

The second stage is anger and encompasses feelings of frustration, irritation, and the underlying anxiety that may manifest in an anger response. Within the participants there was much discussion about the complete shift in routine experienced following a diagnosis. A subtheme found within this stage therefore was The Loss of Control.

The Loss of Control

One of the largest frustrations voiced by the participants was the general loss of normalcy and sense of control within their everyday lives. A T1DM diagnosis changed the way many scheduled their days, now revolving around the management of their child's blood glucose level. No longer could many participants decide they wanted to go out for the night or leave town with their partner without more intensive planning that centered around having someone available who was specially trained to care for their child, which was extremely hard to find. Travel options also became limited, and participants discussed the preparation trips required just in case anything went wrong. There was no safety net for these parents. Many described feeling like they were the last, and sometimes only, line of defense and that no one knew how to take care of their child like they were able to. Caregivers reported that this caused stress and anxiety to build-up from never having a minute to themselves.

“We couldn't just go and do something as a family, it had to involve this thing that I liken to a toddler. [Diabetes] is like having a toddler that never grows up. You bring it with you everywhere. You constantly are tending to it.” (Participant #4)

Stage 3: Bargaining

This stage is one that may look extremely different for each individual experiencing grief. It can involve trying to find some sort of meaning within a given situation, starting to reach out to others for help, or simply seeking ways in which to make the grieving process slightly more bearable. A few subthemes developed for this stage, including Trying to Find Meaning, Trust/Management/Education of Others, and New Technology.

Trying to Find Meaning

A large part of the initial experience for the participants was asking themselves how or why this happened. Many discussed thinking through their family history and other factors that can lead to someone developing T1DM and not being able to say for sure why their child got it. A few were not entirely surprised by the diagnosis, but for the majority, it was something that they could not pinpoint or find an answer for. This led to parents struggling with frustration and irritation while working through the grieving process. Something that was revealed through several of the participants answers was an underlying sense of hope that things would get easier with time, however in the meantime looking for some sort of meaning behind the diagnosis helped to ease the emotional weight of it.

“As I say, [my son], he's really special, which is why I totally believe that only the really special people get diabetes, because it's such a burden that only a special person could ever deal with it for their entire lifetime.” (Participant #6)

Trust/Management/Education of Others

This is also the stage that people tend to begin reaching out or accepting support from external sources and providing education about the disease management and care to others now that they themselves are a little more comfortable. Some of this comes out of necessity, such as getting newly diagnosed children back to school as soon as possible, so engaging with the administrators and nurses quickly to figure out a good system that would work for everyone was important. Other interactions took more time. In some cases, grandparents were at the hospital getting trained or helping to watch the children while the parents were with the educators. In other situations, family was less comfortable with being involved or lived too far away, and it was more on the parents to reach out and find other connections for help. As more people were educated on how to care for their child with T1DM, especially in the school setting, these parents had to work on trusting others to take over at times.

“When school started... it was a little more difficult in one way because I was dealing with other people having to watch over my son instead.” (Participant #1)

“A big part of our success was our school. Our school basically took care of everything diabetes while he was there, so I didn't have to leave work during lunch.” (Participant #12)

New Technology

Technology today is something that constantly changes and improves, including enhanced technology for the care of those with T1DM, which was a topic that came up within conversations often. While participants discussed starting out with multiple daily injections

(MDI) to treat blood glucose levels, many switched over to using a variety of insulin pump therapies as soon as possible. They reported that this technology provided better glycemic control, and when a pump was paired with a continuous glucose monitor (CGM), it greatly reduced the number of injections and daily finger sticks to check blood glucose as well. This was an important aspect of this new technology, especially in pediatric cases of T1DM, since these elements of diabetes care were often more difficult and invoked a fear response. These systems were reported to reduce the amount of stress experienced by both the caregiver and the child surrounding certain activities as well, such as mealtimes. It also provided a sense of reassurance in between meals that if levels were to change drastically, they would be alerted. Gaining access to this technology was often a turning point for participants and was seen as a means to simplify diabetes care through gaining more control, therefore many advocated for it during this stage. It changed the way both the caregivers and those diagnosed interact with and manage T1DM and provided some relief to this population throughout the grieving process.

“Since he’s been on a pump, things have definitely changed significantly for him in terms of freedom. And as his blood sugars have started to level out...having him on the pump and being able to just consistently give him insulin has been really important.” (Participant #10)

Stage 4: Depression

The fourth stage, depression, is the experience of grief that is most commonly recognized as a part of the grieving process. This stage is represented by feeling overwhelmed, a sense of numbness and helplessness, or feelings of guilt. When the topic of grief came up in the interviews, participants most frequently talked about feelings associated with this stage. Subthemes that emerged for this stage were Feelings of Guilt and Isolation.

Feelings of Guilt

Guilt is something that came up quite a bit when talking with participants, and often was correlated with parents feeling extremely sad for their child and ultimately responsible for the situation. The overall cause of T1DM is unknown, and many participants acknowledged that much of the blame they placed on themselves was unwarranted, yet it was still a common response often experienced throughout their individual grief responses. A few parents talked about mourning the loss of a “normal” life for their child, even if they won’t remember what life was like before they were diagnosed, and this often manifested as guilt as well. A diagnosis of T1DM unfortunately can be restrictive in certain ways, and participants discussed their struggle with feeling like their child was now limited in what they could do. Parents were also feeling guilty about the amount of time and energy spent caring for their child diagnosed with T1DM and how that impacted their other children, which weighed heavily on them at times.

“I definitely feel like [my son] was, his needs were put first a lot, so I think that was tough. I mean, [my daughter] never has complained about it or anything, but I definitely had felt guilt about that”.

(Participant #7)

Isolation

One of the most common experiences discussed throughout the interviews was experiencing a sense of overwhelming isolation. Diabetes is a disease that is not understood well by the general public, and many get T1DM confused with type 2 diabetes which was extremely frustrating for parents. They are two distinct diseases that require different things in terms of management and care. A T1DM diagnosis alters every part of these families’ daily life, and

unless one interacts with someone who has this disease regularly, it is not possible to fully grasp what it requires as a parent to care for someone. Many participants shared this sentiment within conversations, saying that they were unable to explain or show anyone else what they went through, isolating them. Support groups were often the only way for these parents to relate to others within a community, and a way that many discussed being able to release feelings of frustration and reduce the isolation they experienced.

“I don't feel like anyone understood the kind of stress we were under and what a disruption this was to our lives and just how hard every day was, so it felt very isolating in that way.”
(Participant #2)

Stage 5: Acceptance

The final stage is acceptance. This is when individuals who are grieving begin to come to terms with what has happened and the idea that they will be okay. One still experiences a range of emotions throughout this stage and there are both good days and bad days, but these begin to stabilize as time goes on. It is a period of adjustment, looking ahead, and planning within a new reality. Subthemes that emerged within this stage include a Transition to Self-reliance, Impacts on Relationships, and Resilience.

Transition to Self-reliance

It is this stage where parents started to really feel more comfortable with management, having transitioned from a reliance on the nurse educators to doing a lot of management tasks themselves. It is also important to note that not every participant had reached a level of self-

reliance at the time of their interview due to a variety of reasons. Many of the participants had differing experiences within this shift. Parents discussed gradually reaching out to educators less as time went on, starting to grasp certain managements responsibilities including calculations and ratios on their own. While experiencing this transition did not necessarily represent that the grieving process ended for these families, it was a pivotal step in reaching a level of acceptance of their child's diagnosis and they knew that they were capable of handling much of the management on their own. However, this does not mean parents actually were on their own, there always was a nurse educator or pediatric endocrinologist on call to reach out to if needed. Many participants expressed a gratitude for these health care professionals providing them peace of mind throughout the process.

"I would listen to them work it out in their head as they were kind of giving him a number and I would take notes so that I could try to do it on my own...we're in a lifetime disease, I'm not going to call every time I feel like I need to change something." (Participant #3)

Impacts on Relationships - Good, Bad, Multigenerational

Having and forming relationships is a large part of the human experience, and traumatic events such as a T1DM diagnosis can have a considerable lasting impact on these. This was something that came up frequently within conversations with parents and was comprised of both positive and negative effects that varied greatly between individual situations. For instance, a lot of participants talked about how their nuclear family became closer due to this experience, while others discussed a distinct rift in sibling relationships or within their marriages following the diagnosis. This was an incredibly stressful time for many and was reported to be especially draining for those who felt they carried an uneven amount of the management load, as was the

case for multiple participants. Family relationships outside of the immediate family were also a significant factor in many of these parents' experiences, and it was increasingly difficult the less support they felt they had from individuals such as grandparents. In terms of relationships outside of family, such as friendships, it was during this time that parents expressed gaining an understanding of who was and who was not there for them and prepared to go the extra mile in helping to relieve some of the pressure.

"It had a negative effect on my son's relationship with my daughter. He got really jealous, I am willing to bet that there is some worry in there as well because whether he wants to admit it or not, he does love his sister." (Participant #5)

"In terms of the family, it was one of the things I think that caused our marriage to fall apart...it almost feels less lonely when it is just me, because I know it's just me. When it something that I hope he'll step up for, like take the night cause I'm exhausted, its lonelier when it doesn't happen. So, communication is really, really, really important." (Participant #10)

Resilience

One of the strongest themes noted throughout the interviews was that of resilience from both the parents as well as their children. Their capacity to overcome adversity when faced with a difficult situation was highlighted in their answers, and many of their responses had undertones of hope and positivity. The participant's answers to the questions were extremely open and honest, even when discussing heavy topics, yet they were still able to find good within their personal situations. Some discussed finding a sense of purpose, others talked about those they have connected with, and even distinct opportunities that arose either for themselves or for their children due to this experience. This is something that none of the participants wished for and

that changed the course of their entire lives significantly, all while much of their own emotional traumas went overlooked in an effort to appear strong for their children. Talking with members of this population about their experiences was a true testament to the power of human resilience.

“First, I would say that in general, you find a much more positive group of people than we may have taken for granted otherwise. I would say that it has tested each of us in our capacity to, this is going to sound fancy but, tolerate imperfection.” (Participant #10)

“It’s kind of given our family a purpose in a weird way...it's given us a sort of this cohesive thing that we share...It sets us apart from other from other families that we know.” (Participant #11)

Chapter 5: Discussion and Conclusion

T1DM is a chronic illness that is extremely labor-intensive and often diagnosed in childhood, placing a huge amount of the management burden on the caregivers of those diagnosed. Due to the self-management nature of the disease, it has a considerable emotional impact on both the child diagnosed as well as their family members tasked with caring for them (Ayala et al., 2014). It is acknowledged that this population has been relatively underserved in the past, with previous research focusing more on the effect of a diagnosis on the child's life rather than the lives of their parents (Helgeson et al., 2012). The importance of continuing to gather data on the lived experience of this population is also recognized, in order to further the overall understanding and ensure medical teams are able to provide the high-quality care and support that this population deserves. With this in mind, the purpose of this study was to qualitatively explore the experiences of parents and guardians of children with T1DM specifically living in Vermont.

Throughout the interview process, it was highlighted that many individuals had experiences that correlated with the stages of grief framework as defined by Elisabeth Kübler-Ross (Gregory, 2021). However, it is important to understand when examining the stages that even though they are listed in a specific order everyone has their own experience with grief and it is an ever-changing process. It is not uncommon for individuals to go through these stages in an entirely different order, skip stages, or repeat stages within their own personal grief experience. The grieving process parents may go through when their children are diagnosed with T1DM is something that may not be recognized within society, as the diagnosis is not well understood by the general public. This was a significant topic of discussion with the participants, specifically the confusion and misinformation surrounding what is actually required and how

much it impacts the families. Participants also described mourning the loss of what they thought their child's future was going to look like, which then suddenly felt defined and controlled by the T1DM diagnosis.

When comparing the results of this study with previous findings, the experiences of the participants interviewed in Vermont were similar. Past studies have found that there are higher incidences of stress, anxiety, feelings of burnout, and depressive symptoms among parents and guardians who have a child diagnosed with T1DM (Boogerd et al., 2015, Iversen et al. 2018, Lindstrom et al. 2017, Smaldone & Ritholz, 2011). A contributing factor to the emotional burden was the knowledge that this chronic illness comes with a variety of both short and long-term risk factors, making proficient management exceedingly important (Marshall et al., 2009). These were all things that were mentioned within conversations with participants, many of them saying that one of the most difficult things to deal with following the diagnosis was the emotional component, everything else they could learn. Research by Boogerd et al., (2015), highlights the importance of not only supporting the child after diagnosis, but the entire family as well.

Parents and caregivers often described experiencing self-doubt while adjusting to diabetes care following their child's diagnosis and feeling that nobody else understood the care necessary, isolating them from others (Smaldone & Ritholz, 2011). No one can truly understand what it is like unless they live with T1DM day in and day out, one participant illustrating the demand of this diagnosis when talking about how they currently operated as their child's pancreas 24 hours a day, seven days a week. There are simply no breaks for these caregivers, which puts them at a greater risk for suffering from the mental health problems noted earlier as a result. Ultimately, a large factor in why many participants experienced what they did was tied to this lack of understanding of what they go through daily. A common dissatisfaction found in

previous research was a frustration with healthcare providers for blaming them for a lack of parental expertise (Smaldone & Ritholz, 2011). Based on the findings from this study and previous research, there is clearly still a lot that can be done both in Vermont and more broadly to work with this population and make sure that their emotional and psychosocial needs are being adequately met.

Limitations and Future Research

This study does have its limitations. One potential limitation was that all of the participants were from Vermont, which leads to a relative lack of variety when it comes to the location of care provided. Another potential limitation may be the virtual interview aspect, an adjustment made following the onset of the COVID-19 pandemic. Particularly during the phone interviews, it felt difficult at times to connect with the participants in the same way as a face-to-face interaction for a number of reasons. Some of these included dropped or poor cell reception, a lag in the audio, having to repeat questions multiple times, or having to ask the participant to repeat their answer. While technology and the virtual format did help to streamline the interview process, the quality and depth of the data collected may have been influenced by this approach.

As mentioned, future research can always continue to develop and cultivate a better understanding of the individual experiences within this population. More specifically, studies that continue to directly ask parents and guardians what they feel they could have used after the diagnosis to feel better supported and ease that transition period are important in recognizing what is missing from their care. Future studies could attempt to improve upon this research by focusing on gathering participants from varied areas and continuing to have these important conversations in person when it is realistic to do so. While this study did not ask the participants

about their race or education status, something other studies have cited as limitations was the use of either a largely white population (Rankin et al., 2014), or a well-educated sample (Lawton et al. 2018). Subsequent research could aim to look at the impact of a T1DM diagnosis on racially and/or socio-economically diverse groups. Furthermore, future quantitative studies should focus on identifying and implementing specific changes to better support this population through the process following the diagnosis of their children.

There were a few questions to come out of this study which include: How can we help get caregivers and families through the grief process to feelings of self-reliance and, eventually, acceptance? Does anything accelerate or prolong the process? Is it possible to identify individuals who might need more support than others initially? And if so, what can be done to offer them extra assistance? These inquiries could also potentially lead to future research, but regardless, there is still much work to be done in providing quality care for individuals in this population.

Clinical Implications

This research shows that individuals in this population that reside in Vermont report similar experiences to those found in previous research on this subject. The clinical implication of these findings is that a disconnect still exists in some cases between providers and the caregivers of children diagnosed with T1DM, which needs to be addressed. Something that was discussed repeatedly within the interviews was the importance of connections with other families going through this experience, and the relative lack of networking within the hospital setting. Possibly facilitating a mentorship program with other families who have experience with having a child with T1DM and are willing, could help make the initial adjustment smoother for many

moving forward. This study's findings can be used to help those working in the healthcare setting expand their understanding of what these parents are experiencing. It could potentially be used, along with other studies, to come up with policy changes that could be implemented in a clinical setting. One example could be adding routine screenings to assess parental depression, anxiety, and stress levels, providing referrals to social work or mental health professionals to assist with any discernable issues for those who are interested.

Conclusion

The findings of this study demonstrate that the experience of parents and guardians who have children diagnosed with T1DM in Vermont is similar to previous studies conducted on this topic. Participants discussed the large emotional toll it takes on them both mentally and physically, and the repercussions a diagnosis can have on every aspect of their daily lives including their family dynamic and relationships. This study also found that many individuals in this population go through the grieving process in response to the life-changing event. Unfortunately, the extreme anxiety, stress, and grief they experience is rarely understood by members of their communities, which can lead to feelings of intense frustration and isolation. Future research could focus on identifying specific ways in which to adequately support this population.

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Appendix

Interview Questions

Pre-interview Demographic Information:

1. How long ago was your child diagnosed? Date of diagnosis.
2. How old was your child when diagnosed and what is their current age?
3. Best description of family structure:
 - Single parent
 - Two parents
 - Shared custody
 - Other (describe)
4. Sex of parent and child.
5. Age of parent.
6. How many children do you have? Where in sibling order is the diagnosed child?
7. What is the current method of insulin therapy (insulin pump, injections)?
8. How would you describe your child's current blood sugar levels?

Interview Questions:

1. What was it like for you when you found out that your child had diabetes?
 - Describe your early learning experiences and how they occurred.
 - How did you feel about your ability to do all of this when ____ was discharged from the hospital?
 - What things were most difficult to learn?
2. When you first went home from the hospital, what was it like to take care of ____?

- How did you feel about managing all of this?
 - Was it difficult finding enough time to meet the needs of other family members?
3. Were you employed outside the home, and how did you deal with that when ____ came home from the hospital?
 4. Tell me about the involvement of your family, friends, and co-workers.
 - How involved do you think family members should be?
 5. Who were the people you could turn to for support or guidance?
 - What types of things did you discuss?
 6. In which ways has diabetes affected your family life?
 7. Looking back over your own experience, what things would have been helpful to you in making the adjustment to parenting a child with diabetes?